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What patients with pervasive developmental disorders think of and expect from nurses

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Abstract

This study was performed to determine the views and expectations of patients with pervasive developmental disorders (PDD) regarding nurses. Semi-structured interviews were conducted with 10 patients with PDD. Five categories were extracted based on quantitative descriptive analysis of the data: people whose presence is insignificant; people who do not understand me; people who bring a sense of relief; people who provide support; and an expectation of understanding. While patients had negative thoughts regarding nurses as insignificant and as people who did not understand them, they also associated nurses positively with relief and support, revealing their ambivalent views regarding nurses. Furthermore, patients had an expectation of being understood by nurses. These findings suggest that it is important for nurses to understand the hardships experienced by PDD patients and build relationships with them through communication and nursing care. Using these newly built relationships taking their characteristics into account, nurses should provide advice to patients, thereby encouraging them to express their needs and hopes for the future. As PDD patients may make few expressions, it is necessary to convey what the patients would like to say and what they are thinking to family members and physicians.

KEY WORDS

Pervasive developmental disorders, nursing, narrative, qualitative study

Introduction

The Diagnostic and Statistical Manual of Mental Disorders Fourth Edition, Text Revision[1] classifies pervasive developmental disorders (PDD) into autistic disorder, Rett syndrome, childhood disintegrative disorder, Asperger syndrome, and pervasive developmental disorder–not otherwise specified. The 2012 survey of public elementary and junior high school students conducted by the Japanese Ministry of Education, Culture, Sports, Science and Technology has shown that the prevalence of PDD among elementary and junior high school students enrolled in regular classes is approximately 1.1%[2]. Kawamura et al. also reported that the incidence of PDD among children aged 6–8 years in Toyota City, Japan was 1.8%[3], whereas the prevalence of PDD among children aged 7–12 years was 2.6% in Korea[4]. These studies clearly show that PDD is not a rare disorder.

Until recently, the position of individuals with developmental disorders within the Japanese legal system was not defined, and there were no laws with the purpose of supporting such individuals. As a result, individuals with developmental disorders were placed in the zone between the legal systems for individuals with physical disabilities, intellectual disabilities or those with mental disorders, making it difficult to provide adequate support to them. The Act on Support for Persons with Development Disorders finally went into effect in 2005[5]. With this Act, it became possible to support the development of preschool and school children with developmental disorders through into adulthood (to include career development and community-based living support) as well as their

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families. Specifically, the Maternal and Child Health Act places importance on the early detection of developmental disorders and for the provision of early support to promote a positive social life through screening for psychological problems among preschool children at routine health checkups (the 18-month and 3-year checkups). With regard to school children, the Act recommends the provision of educational support appropriate for the severity of the disability and the establishment of this system. For adults with developmental disorders, the Act places importance on supporting career development. For families, the provision of information and consultation to help them to understand and properly deal with developmental disorders is considered to be important.

A major issue in the support of individuals with developmental disorders is their difficulties in interacting with others. Individuals with PDD are characterized by their inability to understand the message behind words or non-verbal expression. It is also difficult for individuals with PDD to share hobbies and interests and consequently to share feelings and reactions, in turn making it difficult for them to build relationships with others. They are also not good at expressing their thoughts and ideas to others, causing misunderstanding. Because of these characteristics, individuals with PDD often fail in relationships, and after experiencing failure many times, often develop a victim mentality and begin avoiding interpersonal relationships.

In one of the studies aimed at understanding the inner world of individuals with PDD who are pessimistic about interpersonal relationships and have trouble speaking their mind, Brown et al. interviewed children aged 6–14 years with PDD about their earliest, positive, and negative memories and reported that, compared with neurotypical children, their recollections seldom involved emotion, thought, perception, or empathy[6]. Similarly, Goldman et al. interviewed children aged 9–12 years with PDD about eight distinct events, including birthday and hospital visits, and a qualitative analysis of the data revealed that, compared with neurotypical children, their narratives seldom involved people, they a lacked concluding remarks, and they tended to contain general facts[7]. In interviews by Crane et al. on everyday life events, adults with PDD talked about events without giving detailed or internal descriptions, instead of talking about specific personal experiences[8]. In Japan, no studies have conducted direct interviews of individuals with developmental disorders to listen to them directly and analyze the data scientifically. What is available is a couple of publications authored by individuals with PDD who are skilled in writing[9,10], in which they talk about feelings of total abandonment and social isolation resulting from being scolded by people around them. Other characteristic features included hypersensitivity, such as intolerable irritation around the neck due to a clothing label, as well as irritability and anxiety caused by their inability to recognize the flow or outlook of everyday life with others.

Although the importance of early intervention has been recognized, some adult PDD patients did not receive such intervention during their childhood, and currently face serious social problems in their lives. Such individuals with PDD are sometimes admitted to psychiatric wards because of aggression towards others or self-injurious behavior due to panic or agitation, or because of depressive conditions due to difficulties with social interactions. This is the main situation in which nurses can have close contact with PDD patients. Although only a few studies have investigated nursing care given to inpatients with PDD[11–13], these studies showed the efficacy of responses tailored to individual inpatients with PDD. As reported by Uchida[14], the findings of studies aimed at understanding individuals with PDD or clarifying the nursing care provided to them were still vague. Nurses play an important role because they can build a close relationship with PDD patients through the provision of support in daily life, and it is therefore necessary to increase the number of studies conducted on PDD from the viewpoint of nursing.

With this in mind, in this study we interviewed inpatients with PDD and investigated what they think of and expect from nurses. To establish proper and effective nursing care for inpatients with PDD who have difficulties with communicating with others, it is extremely important that the patients use their own words to talk about nurses. To the best of our knowledge, this is the first study of this kind and thus its contributions are of considerable value to the field.

Methods

1. Study design

This qualitative descriptive study aimed to reveal what individuals with PDD think of nurses, from the perspective of inpatients with PDD. To achieve this, we used a method that preserves the natural context and

provides rich descriptions using the patients' own words in order to facilitate comprehensive understanding of the phenomena.

2. Study participants

This study was conducted in two psychiatric wards in Prefecture A. Both wards admit patients with developmental disorders, but were general psychiatric wards for adult patients and not specialized facilities for treatment of PDD. Enrollment criteria were: clinical findings of neurological impairment and diagnosis of autism, Asperger syndrome, or PDD not otherwise specified based on the Diagnostic and Statistical Manual of Mental Disorders Fourth Edition, Text Revision[1]; inpatient on the psychiatric ward; intelligence quotient (IQ) of ≥ 70 (to ensure expression of the perception of nurses); and sufficient mental stability, as judged by the physician, to participate in the study.

As shown in Table 1, 10 inpatients (7 men, 3 women) aged 17–40 years were enrolled. The diagnosis was PDD in 2 patients, Asperger syndrome in 5 patients, and PDD not otherwise specified in 3 patients.

3. Data collection period

Data were collected between September 2012 and June 2014.

4. Data collection methods

1) Participant observation

The researcher observed actual interactions between patients and nurses or other patients on the hospital ward. The duration of observation ranged from 30 to 60 min, and the cumulative time used for the observation of 10 patients was approximately 40 h. In addition, to ascertain the communication characteristics of individual patients with communication disorders and thus their difficulties in properly expressing their own thoughts and ideas, the researcher conducted informal interviews on the ward to clarify the meaning of their behavior and words. Information was extracted from a total of 32 situations. Information obtained during participant observation was recorded in field notes. Participant observation was used as a data collection method because this study aimed to ascertain what individuals with PDD think of nurses through the words they themselves use, and thus researchers needed to understand the expressions and words used by individual patients.

2) Semi-structured interview

In a private room in the hospital (to maintain privacy), one semi-structured interview lasting 30–70 min was conducted with each study patient just before hospital discharge. The researcher asked patients to talk about nurses—what they thought of nurses during admission and what expectations they had of nurses—using an interview guide as a reference. After obtaining consent from the patient, the interview was recorded using a digital voice recorder and was transcribed for data analysis.

Prior to the interview, to establish a relationship with each patient and to generate rich data during the interview, the researcher visited patients approximately

Table 1. Patient characteristics

ID	Age (years)	Sex	Diagnosis	Number of hospital stays	Causes of hospital stays	Work experience (Yes/No)
A	24	Male	Asperger syndrome	11	Harm to others	Yes
B	34	Male	Asperger syndrome	3	Harm to others	Yes
C	17	Female	Asperger syndrome	3	Harm to others	No
	32	Male	Pervasive developmental disorders not otherwise specified	2	Harm to others	No
	37	Female	Asperger syndrome	8	Harm to others	Yes
F	36	Male	Pervasive developmental disorders	1	Harm to others	Yes
G	40	Male	Pervasive developmental disorders	1	Harm to others	Yes
H	38	Male	Pervasive developmental disorders not otherwise specified	1	Harm to others	No
I	17	Male	Asperger syndrome	1	Harm to others	No
J	25	Female	Pervasive developmental disorders not otherwise specified	1	Suicidal ideation	No

twice a week up to a total of 3–10 times (Table 1) to engage in daily conversation or just listen to them. We judged that the relationship was solid enough for sufficient data collection when patients voluntarily commented on their own symptoms, or talked about their concerns about their families in front of nurses. Actual interviews were conducted with the researcher to verify the meaning of the patient's words. When patients used words unique to them, they were asked to repeat using general terms as much as possible.

5. Data analysis

We carefully examined the data obtained during participant observation and semi-structured interview, especially the parts where patients expressed their view of nurses through their interactions during their hospital admission. While paying attention to the context, we extracted utterances with distinct meaning and generated codes representing the message contents. The codes were read repeatedly, and the similarities and differences of the semantic contents were comparatively analyzed. Analysis was ended before losing the specifics of semantic content from each code, and these data were the final codes used for data analysis for the individual patient. Lastly, the codes from 10 patients were combined and subcategorized, and then categorized based on the similarities between the semantic contents.

6. Accuracy of the analysis

During the analysis, those researchers experienced in qualitative studies assessed the appropriateness of analytical framework used. Additionally, the analysis results were shown to individual patients to verify the representation of their message was accurate. When necessary, additions and modifications were made to the data to ensure the accuracy of the analytical results.

7. Ethical considerations

This study was approved by the Medical Ethics Committee of Kanazawa University (Approval No. 404). Prior to the study, patients were informed that study participation would be voluntary and that refusal to participate or withdraw from study would not disadvantage them in any way. Patients also received an explanation verbally and in writing before signing the consent form that data would be stored in a secure place, individual patients would not be identified, data would be used only in the present study and destroyed as soon as the study was over, and the results would be published while maintaining their anonymity. We also assured patients that the contents of their talk would be confidential, especially from nurses working on the ward. We also obtained informed consent from the families of patients younger than 20 years old. Furthermore, to avoid and prevent flashbacks of traumatic memories, we carefully observed any changes in patients during interview, cooperated with medical staff, and exchanged information on the conditions of patients as needed.

Results

The results for the meaning of the nurses' presence and what patients with PDD thought of nurses are shown in Table 2. Forty-six codes were extracted from the patients' descriptions and thoughts on nurses and were classified into 14 subcategories and then 5 categories. In the following, the explanations of categories and subcategories are shown in [brackets] and {braces}, respectively.

Patients with PDD felt that they were {not personally involved with} nurses. Consequently, they thought nurses were {not a target of building a relationship with} or there was {no need to interact with} nurses. This led the patients to consider nurses as [people whose presence is insignificant]. The patients also thought of nurses as [people who do not understand me] because of feelings that the nurses were {not recognizing me as an individual}, {not aware of the pathological characteristics of PDD}, and were {interacting inappropriately}. However, patients also viewed nurses as {supporting me in everyday life}, {standing by me and watching closely}, and {accepting me not as a patient, but as a human being}, which made them think of nurses as [people who bring a sense of relief]. Patients also viewed nurses as [people who provide support] because they were {able to talk about troubling symptoms} with the nurses and were {able to learn from suggestions and comments} given by the nurses.

These findings suggest that patients were unable to feel the presence of nurses and perceived a lack of understanding from nurses about their PDD. Yet, they also felt a sense of relief from nurses and felt supported by them. Patients had {a desire to be recognized as an individual with PDD} and {a desire to get professional opinions from nurses} who were knowledgeable about PDD, demonstrating that patients had an [expectation of understanding] from nurses. Below, patients' narratives are indicated in bold type and are explained according to

the different categories identified.

1) [People whose presence is insignificant]

This category was composed of three subcategories: {not a target for building a relationship with}, {not personally involved with}, and {no need to interact with}.

With regard to the subcategory of {not a target for building a relationship with}, patients described that they expect nothing from nurses. In addition, because patients had no idea about what kinds of support nurses provide, patients do not consider receiving support from nurses. Furthermore, findings from participant observation reveal that even when nurses were communicating with patients, patients showed no expression and responded poorly.

Researcher: What do you expect from nurses?

Patient G (answered immediately with no emotion) : Nothing special.

Patient H: I did talk to them when I needed some help, but it was not about concerns, counseling, or symptoms.

Researcher: Did you have no need to consult nurses?

Patient H: Yes, that too. I am not taking any medication.

With regard to the subcategory of {not personally involved with}, patients explained that they did not speak at leisure with nurses even though they did talk to nurses during thermometry or after the family's visit.

Table 2. What patients with pervasive developmental disorders think of and expect from nurses

Category	Subcategory	Code	ID
People whose presence is insignificant	Not a target of building a relationship with	I did not seek anything from them	G,H,J
		Nurse was not someone to ask for help	G,H,I,J
		I had no idea what to consult	D,H,J
	Not personally involved with	Nurses rarely interacted with me	F,G,H,J
		I did not speak at leisure with nurses	E,H
		I was not moved during my interactions with the nurse	H,J
	No need to interact with	Nurses were not helpful	H,J
		It was neither easy nor difficult to talk to nurses	G,H,J
People who do not understand me	Not recognizing me as an individual	I was recognized as a disease, but not as an individual	A,C,E,J
		I was not respected	A,E
		Nurses did not pay attention to me	D,E,H
		Nurses did not try to understand me	C,E
	Not aware of the pathological characteristics of PDD	Nurses did not understand the pain caused by the symptoms	A,C,E,H,I
		Nurses behaved strangely towards patients	E,F
		Nurses don't initiate conversation	C,E,G
		Their responses were all the same	H,I
	Interacting inappropriately	I was pressured by their encouragements	A,C
		Patients were not prioritized	A,C
		Nurses did not help me when I was in agony	C,E
		There was a gap between my need and what nurses provide	C,J
		Nurses did not keep their promise	E,H
		I was treated terribly	C,E,G
People who bring a sense of relief	Supporting me in everyday life	Nurses spoke on behalf of me	D,H
		Nurses supported me in my self-care routine	H,J
	Standing by me and watching closely	Nurses recognized my effort	A,F
		Nurses understood me	C,D,I
		Nurses complimented what I am good at	G,I
		Nurses listened to me	C,D,I
		Nurses worried about me	E,I
		Nurses treated me just right	D,I
	Accepting me not as a patient, but as a human being	Nurses looked after me	A,F,H
		Nurses smiled at me	F,G,I
People who provide support	Being able to talk about troubling symptoms	We discussed about how to handle difficult situations	F,I
		We discussed about PDD	A,D
		I felt better after talking with nurses about my symptoms	A,B
	Being able to learn from suggestions and comments	Nurses taught me what things were impossible	A,D
		I could consult about the future	B,C,D,F,I
		Nurses directly pointed out my mistakes	A,E
		I got to know about others and learn from nurses through our relationship	D,I
Hoping for understanding	Hoping to obtain recognition as an individual with PDD	I really wanted someone to help me	B,C
		I needed commitment in line with disease characteristics	A,I
		Nurses should consciously try to understand me as someone with disabilities	A,E
	Hoping to obtain professional opinions from nurses	Nurses should not answer right away, but give me time to think about my own actions.	A,B
		Nurses should talk to me after understanding the agony of having PDD	E,I
		I wanted to talk with the nurse about my future in details	A,E
		I needed someone to answer me as a nurse	C,E

Consequently, patients described that they were hardly involved with nurses or did not remember how they interacted with each other.

Patient E: I seldom talk to nurses.

Patient J: We interact only when having our temperature taken.

With regard to the subcategory of {no need to interact with}, patients felt no need to have others, including nurses, listen to them. What is worse is that patients felt uncomfortable when they did interact with nurses.

Patient H: Ever since I was small, I've never felt better or liberated by talking with someone.

Patient I: The interaction with nurses somehow makes me uncomfortable.

2) [People who do not understand me]

This category is composed of three subcategories: {not recognizing me as an individual}, {not aware of the pathological characteristics of PDD}, and {interacting inappropriately}.

With regard to the subcategory of {not recognizing me as an individual}, patients felt that nurses did not respect them as human beings or people with a disorder.

Patient C: I'm not recognized (by nurses). If they think they do recognize me, they should tell me so. Just come and tell me so.

Patient E: They don't look like they are trying (to understand me). They seem to be thinking that we're just making small talk".

With regard to the subcategory of {not aware of the pathological characteristics of PDD}, patients thought that nurses did not understand the hardships that they go through because of the disorder. Patients also felt that they were not getting responses appropriate for their disorder.

Patient A: It must be difficult for nurses to understand that we are trapped (by our disorder).

Patient C: Nurses do things that people with autism dislike the most. I really don't like someone fiddling with my stuff without my permission.

With regard to the subcategory of {interacting inappropriately}, patients thought that nurses mistreated them by neglecting the pathological characteristics of their disorder and that nurses' words showed their ignorance about the disorder and therefore that they missed the point.

Patient E: I am sensitive to sound, but the nurses told me to get used to it. It's impossible.

Patient J: I thought what the nurses said was bizarre.

3) [People who bring a sense of relief]

This category is composed of three subcategories: {supporting me in everyday life}, {standing by me and watching closely}, and {accepting me not as a patient, but as a human being}.

With regard to the subcategory of {supporting me in everyday life}, nurses talked to patients' families and physicians on behalf of patients when the patients could not express their thoughts well due to their communication disorder. Patients also talked about individualized care they had received.

Patient D: I don't think I'm being self-centered, but I appreciate that nurses arrange things well for me.

Patient H: I was happy to receive special consideration.

With regard to the subcategory of {accepting me not as a patient, but as a human being}, patients felt that they were being understood or recognized while talking to nurses.

Patient A: Nurses recognized that it is a hope, beyond a dream, that by making efforts my life becomes more stable.

Patient D: Even though this is something that happened to me, the nurses listened to me very kindly, politely, and sincerely. What pleased me the most was they started talking to me in a gentle way.

With regard to the subcategory of {standing by me and watching closely}, patients felt supported even if the actions of nurses were unintentional, regardless of whether direct support was given. Our observations revealed that patients often caught the view of the nurses by accident and that patients smiled when greeted by a nurse.

Patient A: Some nurses provide care by just

watching closely.

Patient F: The mood and even small gestures made me happy.

4) [People who provide support]

This category is composed of two subcategories: {being able to talk about troubling symptoms} and {being able to learn from suggestions and comments}.

{Being able to talk about troubling symptoms} indicates that patients were able to talk to nurses about something troubling them, think about solutions together, feel relieved by talking to nurses about their disorder and symptoms, and feel supported by nurses.

Patient D: It's not that I don't like talking with friends and family members about my disorder or symptoms. It's because they're not familiar with the disorder.

Patient F: I talked with a nurse about my parents' visit. It was helpful because I always get into trouble (with my family).

{Being able to learn from suggestions and comments} showed that patients thought about their future by talking about their future with nurses and getting suggestions from them. In addition, patients learned the process of getting to know others through their interaction with nurses.

Patient D: We discussed what I should do about my future.

Patient I: This feeling is different from what you feel with your friends. It's more like getting to know other.

5) [Expectation of understanding]

This category is composed of two subcategories: {desire to be recognized as an individual with PDD} and {desire to get professional opinions from nurses}.

With regard to the subcategory of {desire to be recognized as an individual with PDD}, patients expected others to realize their efforts as well as their pain and they hoped to acquire knowledge about the disorder and to be understood.

Patient B: I'm working hard to cope with my mental problems so help me with it.

Patient E: I want someone to understand me. I'd be happy if I could find a nurse who could understand me.

With regard to the subcategory of {desire to get professional opinions from nurses}, patients were looking forward to getting support from nurses who have professional knowledge and an understanding of individual patients, rather than nurses who just listen to patients.

Patient C: I was glad that the nurse listened to me, but just to listen to me, you don't need to be a nurse.

Patient E: I wanted to know what to do now and what I should do after discharge.

Discussion

1. What patients with PDD thought about and expected from nurses

Despite physical interactions with nurses, patients not only did not appreciate the presence of nurses, but also thought of their presence as insignificant. However, the support that nurses provide to inpatients with PDD should go beyond healthcare. According to Suzuki[15], it is important for nurses to discuss with patients about their problematic behaviors and urge patients to behave appropriately while expressing empathy toward the agony that patients with developmental disorders feel due to their inability to understand other people's words and actions and to build interpersonal relationships. Patients may be able to appreciate the presence of nurses only if such relationships exist.

However, it is likely that the present patients thought that they did not receive support from nurses. This gap in perception may have been caused by a difference between the support that patients with PDD need and the support that nurses consider important. This type of situation may be a common pitfall for people with difficult-to-understand psychiatric disorders. Furthermore, patients with PDD may experience perception gaps frequently because of their difficulty in communicating and interacting with others. Because the present patients did not have intellectual disabilities, they were able to adequately perform daily essential tasks (except for interacting with others) without support from nurses. Additionally, they did not exhibit impulsive behaviors or psychotic symptoms, because of treatment efficacy and the change in environment due to hospital admission. As a result, the time they spent with nurses was limited, making it difficult

for patients to perceive nurses as those who could provide support. Furthermore, patients viewed nurses as [people who do not understand me]. Nurses handle situations and offer support in line with social and hospital ward rules, and their support is not tailored to individual patients or patients with PDD. According to Sugiyama, difficulties in interacting with others, which is the characteristic feature of autism, will lead to difficulties in interacting in society, which is characterized by an inability to engage in two-way communications or to appreciate other people's thinking[16]. This feature makes it difficult for individuals with PDD to comprehend social and departmental rules, and they may think that nurses do not give individualized treatment or support, have sufficient knowledge about PDD, or respect patients as human beings. In addition, Toe reported that when patients with PDD are criticized by people around them, they become confused without fully understanding why people act that way, which lowers their self-esteem[17]. Because the present patients did not understand the responses and support they received from nurses, they might have started considering themselves as those who cannot be understood and nurses as [people who do not understand].

However, patients with PDD also perceived nurses as [people who bring a sense of relief]. Throughout their lives, these patients felt that no one listened to their narratives seriously. Patients with PDD are often mistreated by people around them because of their difficult-to-understand disorder[18]. However, during hospital admission, patients with PDD discover nurses who provide support and listen to them and do not act like anyone they knew before. This might have provided a sense of relief to patients with PDD. Psychiatric nurses provide care especially through their interactions with patients[19]. To nurses, it is natural to build individual relationships with patients by listening to them. However, to patients with PDD, even such ordinary behavior may seem meaningful.

To patients with PDD, nurses offer a sense of relief and appeal as [people who provide supports] especially when patients have challenging symptoms. This suggests that to be recognized as supporters, it is necessary for nurses to help PDD patients in dealing with challenging symptoms. By doing so and establishing themselves as supporters, nurses will be able to have patients with PDD accept the support that nurses think the patients need. However, even when nurses try to support patients with PDD, the patients may respond poorly or correct their actions because of the pathological characteristics of PDD, such as repetitive behaviors, excessive resistance to change, and difficulties in communicating and interacting with others. In this study, the patients stated that with the nurses' support, they could learn how to change themselves, indicating that nurses helped them to realize previously unnoticed things. This also suggests that it is important for nurses to continuously support patients with PDD even when the patients do not clearly respond to such support or modify their behaviors.

The findings of this study show that patients with PDD perceived nurses negatively—as [people whose presence is insignificant] and [people who do not understand me]. Patients also view nurses positively—as [people who bring a sense of relief] and [people who provide support]—revealing ambivalent views towards nurses. Opposing perceptions of nurses co-existed in PDD patients, but this did not appear to have caused discord. However, even in such a situation, patients with PDD had an [expectation of understanding] from nurses. Individuals who find it difficult to build relationships due to their PDD were able to feel connections with others through their relationships with nurses, which brought them a sense of relief and helped them view nurses as supporters. This must be the reason why the patients expected nurses to understand them. Such expectation would develop only for nurses with whom the patients spent the most time, engaged in conversation, and received nursing care. Therefore, by keeping this expectation of patients in mind, nurses should deepen their understanding of patients with PDD and continue to support them.

2. Practical suggestions

Obtaining a sense of relief from nurses meant that patients with PDD were able to feel the connection with nurses, which is a significant event for patients with difficulties in building relationships with others. Nurses should understand the pain felt by patients and should build relationships through various communications and nursing care. Because assisting patients with problematic symptoms might help them establish other relationships, nurses need to continue supporting patients with PDD even if the patients respond poorly to their support. Also, nurses who can understand PDD patients in spite of any communication disorders are likely to help patients build good relationships with other people, including their family

members. Thus, although PDD patients' communication skills are very limited, it is necessary to ascertain their hopes and needs in order to provide appropriate support. When supporting individuals with disorders such as PDD, it is important to establish a multidisciplinary approach[20], and nurses should play a central role in providing a sense of relief to patients with PDD who have difficulties in building relationships with others. Through newly established relationships, taking their characteristics into account, nurses must provide advice to patients, thereby encouraging them to express their needs and hopes for the future. Also, as expressions from PDD patients may be few in number, it is necessary to convey to family members and physicians in words what the patients would like to say and what they are thinking.

3. Limitations and challenges for the future

There are three limitations in this study. First, Prefecture A has only two medical facilities that admit patients with PDD. Although we enrolled 20 patients with PDD who were hospitalized in the two facilities, the findings of this study cannot be generalized because of the small number of patients. Second, although we spent a long time securing 10 patients, their ages ranged widely, so their needs vary as they belong to different generations. Lastly, because we did not investigate the actual support that nurses provided to patients, it is not clear whether the amount of support the patients actually received influenced their opinions on the presence of and expectations of nurses.

Into the future, we plan to increase the number of patients in order to improve the quality of the study, and we will investigate whether and how patients' views and expectations towards nurses change with age and according to the amount of support actually provided by nurses. Through these studies, we plan to establish effective nursing care that takes into account the needs of patients with PDD and their pathological characteristics.

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Starting in March 2014 in Japan, the term 'autism spectrum disorder' is to be used instead of 'pervasive developmental disorder'. However, because 'pervasive developmental disorder' was used during the study period, we use this term in this manuscript.

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広汎性発達障害者がとらえた看護師の存在と抱いた期待

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要　　旨

本研究は、広汎性発達障害（PDD) 者が看護師をどのようにとらえており、何を期待しているかを明らかにすることを目的とした。PDD と診断された 10 名を対象に参加観察と半構造化面接を行い、質的記述的に分析した。その結果、【希薄な存在】【理解してくれない存在】【安堵感を抱ける存在】【支援してくれる存在】【理解されることへの期待】の５つのカテゴリーを抽出した。対象者は看護師を【希薄な存在】であり、【理解してくれない存在】という否定的なとらえ方をする一方で、【安堵感を抱ける存在】であり【支援してくれる存在】であるという肯定的なとらえもしており、アンビバレントなとらえ方をしていた。また【理解されることへの期待】を抱いていた。以上のことから、看護師は PDD 者の辛さを理解し、様々な会話やケアを通して関係性を築いていくこと、築かれた関係性を基盤にして、彼らの特徴をふまえた助言を行いながら、彼らがニーズや将来の希望などを表出できるよう促し、数少ない彼らの表現から言葉や思いを家族や医師に対して代弁したり、彼らにとって最も近くて頼りとなる存在として支援していくことが必要であることが示唆された。